



DRIFT TOWARD TIGHTENED HIV SURVEILLANCE PATIENTS INTO PERPETRATORS?

BY MARK SCHOOFS

ONE OF THE MOST influential people in AIDS policy is neither a scientist nor an activist, but a 21-year-old black man from Brooklyn who apparently infected 13 women, most of them white, in upstate Chautauqua County, take an HIV Willie Horton, the meendiary image of Nushawn Williams threatens to trump public health arguments and decide the debate that has crupted over whether to report the names of all people who test HIV-positive to the state health department.

That issue is about to explode.

With ACT UP chanting, "First a list, then a tattoo, how _____|continued on page 381.

April 7, 1998, VILLAGE YOICE, 37

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CONTINUED FROM PAGE 37 would you feel if it happened to you!" a state advisory panel rejected name reporting last Thursday. But the vote was a narrow 10 to seven. "Is this a mandate?" asked Dennis deLeon, a panelist and the president of the Latino Commission on AIDS. "It's a clear statement that we're divided."

Meanwhile, the federal Centers for Disease Control is widely expected to issue strong guidelines favoring name reporting. Bottom line: The issue will be decided by politicians. Indeed, a passel of bills will soon be voted on by the New York state legislature and the U.S. Congress.

Assemblywoman Nettie Mayersohn, the Queens Democrat who authored the state law mandating HIV testing for all newborns, has introduced a bill that would require the state to collect "identifying information" on everyone who tests positive, so the health department can notify their sexual partners. Bronx Republican Guy Velella has introduced Mayersohn's bill into the senate; the bill is considered likely to pass both houses.

In addition, several Republican members of the assembly have put forward a much more sweeping bill that would create a "cross-tabulated" database of all people who test positive and their partners, for the express purpose of hunting for more Nushawn Williamses. The bill would require everyone who tests positive to reveal all their partners or face criminal charges. It would also create a new felony for conduct that poses a "substantial risk of transmission" to a person who did not know the patient's HIV status—even though intentionally transmitting a serious disease is already a criminal act.

Finally, the bill would eliminate the state's anonymous testing option, a long-standing public-health strategy that invites people worried about AIDS discrimination to take the first step toward getting into care. (Though it split on other issues, the state advisory panel unanimously recommended preserving anonymous testing.)

Such extreme proposals make the Mayersohn-Velella bill seem moderate. "The Republicans have made AIDS issues into a political football to an extent I've never seen," says Robert Jaffe, a lobbyist for the Gay Men's Health Crisis, who has worked with the state legislature for 10 years. "It's really startling."

In addition to shifting the center to the right, the Republican bills also show why name reporting is so explosive. It can be used to track the epidemic, but it could also be used to track individuals. And there is strong public support for placing people with HIV under permanent suspicion. Consider a recent *New York Post* editorial: Because of "absurd confidentiality laws," the tabloid opined, "HIV patients have been permitted to romp freely and anonymously."

"That rhetoric is inflammatory—and intentionally so," charges Assemblyman Richard Gottfried, the Manhattan Democrat who authored New York's HIV confidentiality laws. Indeed, the *Post's* rhetoric insinuates that people with HIV need to be policed. This is why Williams makes the perfect poster boy: He's not a patient but a perpetrator.

It's tragic that this image is so powerful, because what's really at stake is not a few infected psychopaths but the much more important question of how to get large numbers of people into prevention and treatment programs, and how to monitor the epidemic. Will reporting all HIV cases by name help achieve those goals?

Those who answer no maintain that forcing people to appear on a government list and requiring the state to notify their sex partners would frighten them away from getting tested. But proponents of name reporting argue that it is the standard method for tracking a host of diseases, from salmonella to syphilis, and that activists have carved out

an "AIDS exceptionalism" that puts civil liberties before public health. The real answer—all but lost in the rhetoric—can be found in scientific studies that contain surprises for almost everyone in this debate.

MARIE ST. CYR, executive director of East Harlem's Iris House, an AIDS service organization, vividly remembers one family her agency helped. It was headed by parents who were HIV positive. Somehow, their health status became known—and when it did, their children were ridiculed at school and their front door was painted with the words "AIDS Apartment." Says St. Cyr, "The level of harassment compelled them to move out of state."

That incident didn't happen in the bad old days of the epidemic, or in some backward part of the country. It happened last year in New York City.

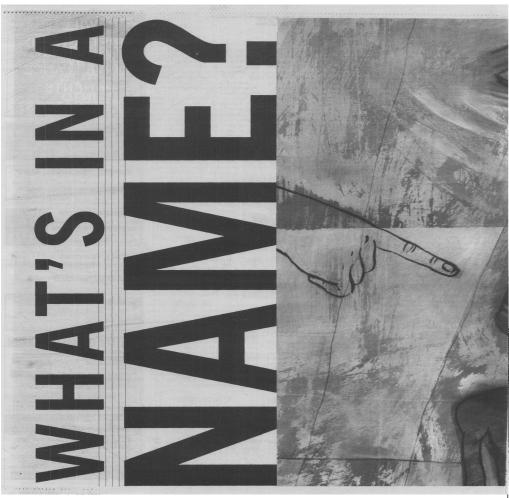
Recent news about AIDS has been so good-longer lives, sharply declining death rates—that it's easy to believe prejudice has lessened, too. Mayersohn, for example, points to the Americans with Disabilities Act, noting that it provides recourse to AIDS patients who have suffered discrimination. But whether that law applies to all people with HIV-or only those who are very sick-hangs in the balance. The Supreme Court will soon decide that question; lower courts have been split. In the case before the high court, a dentist refused to treat an asymptomatic HIV-positive woman in his office. If the Court rules against her, people with HIV will be thrown into a Catch-22: As long as they remain healthy, they will not be protected from discrimination. This case underscores how fragile are the rights of people with HIV: Even when a law seems to protect them, it might not.

No wonder patients are wary, even distrustful. Moises Agosto, an educator for the National Minority AIDS Council, says "some people still believe the government created this whole epidemic." AIDS workers frequently deal with clients who fear doctors will use them as guinea pigs, as in the infamous Tuskegee experiments, when black men with syphilis were allowed to die untreated. Activists note that people most at risk for contracting HIV—racial minorities and gay men—are the most likely to be suspicious of name reporting.

Proponents of name reporting counter that government-held HIV data are more strongly protected by confidentiality laws than any other medical information. But activists maintain that even the strongest laws won't mollify mistrust on the street. They point to a dramatic breach of confidentiality that occurred in Florida. The disgruntled lover of a health-department worker mailed computer disks containing the names of more than 3900 HIV-positive individuals to two newspapers. The ACLU has documented cases of law enforcement agencies disclosing people's HIV status to neighbors and prison inmates, and even over police radios.

The ultimate fear is that some day the government will revoke its confidentiality protections. That happened in 1991, when the Illinois legislature ordered the state health department to find all HIV-positive health care workers by scouring the state's supposedly confidential list of people with HIV. If any infected health-care workers were found, all of their patients would be notified—even though there has been only one apparent case of HIV transmission from health-care worker to patient. Opposition from public-health officials managed to block funding for the procedure. But, a recent ACLU report concludes, "this experience demonstrates the inherently precarious nature of a seemingly ironclad confidentiality guarantee.'

Even if such drastic breaches don't occur, will name reporting trigger such intense fears that people will avoid getting tested altogether? At least 11 separate studies indicate that name reporting does deter some people. In two recent C O N T I N U E D O N P A G E 4 1



SCHOOFS

CONTINUED FROM PAGE 38 studies, more than 70 per cent said they would not get tested if their names were reported to the health department.

Yet, in actual practice, this hasn't occurred. The CDC tracked testing in six states before and after name-reporting laws were implemented. "There were no large declines in overall testing ... except possibly in Michigan," concludes the report. Still, none of these states had criminal penalties like the state Republican bill proposes. Would such measures have deterred more people? "Of course," says the CDC's Allyn Nakashima, who led the study.

What could account for the discrepancy between what people say about name reporting and what they actually do? Ignorance. According to another major study, most people at high risk for HIV do not know if their state collects names. Moreover, this concern is almost never the main reason people avoid testing. The biggest deterrent is plain old "fear of the result," says the study's lead investigator, Andy Bindman. "No one likes to get bad news."

Still, fear of name reporting is one reason why a full fifth of people in Bindman's study delayed getting tested or didn't get tested at all. Given how many barriers there already are to entering the health care system, why add another? The only justification would be if the harm were outweighed by a major publichealth benefit. But it isn't.

"DOES KEEPING NAMES get individuals into care sooner?" asks Bindman. "The answer is no." Patients got into care just as quickly whether or not the state did name reporting. Why? Because most people are channeled into care the moment they test positive. As for health departments following up, Bindman says, "Even when they have the names, they don't contact anywhere near 100 per cent [of patients]. The best state was in the 50 per cent range."

Advocates of name reporting talk about helping people with HIV. But their bills often say something else. For example, Representative Tom Coburn (Republican, Oklahoma), whose pending bill would mandate a national system of name reporting and partner notification, has said it would benefit "those who are infected by providing a link to medical services." Yet

Coburn's bill contains no funding provisions. Even more telling, it would let doctors refuse to treat patients unless they submit to an HIV test. Even corpses are subject to the Coburn bill: Funeral homes can deny all services to bodies that have not been tested.

IF NAME REPORTING scares some people away from testing and doesn't expedite getting patients into care, what does it do? Count heads. And that has suddenly become critical because of better AIDS drugs.

The old tracking method counted cases of full-blown AIDS, rather than mere infection with HIV. But new treatments are delaying the onset of disease. Therefore, counting AIDS cases could make it appear that the epidemic is waning even as new infections continue to rise. That could lull people into a false sense of security and jeopardize government funding. And not knowing where the epidemic is spreading could lead authorities to miss outbreaks and to spend prevention money on the wrong communities. "Surveillance," says Cornelius Baker, executive director of the National Association of People with AIDS, "is a benefit in itself."

But, Baker insists, it's not necessary to report names to reap this benefit. Instead, he supports giving people what is called a "unique identifier." This code—composed of elements such as date of birth, race, gender, and the last four digits of the social security number—helps preserve anonymity while ensuring an accurate count.

Only two states, Maryland and Texas, have tried such a system for HIV. For three years the CDC evaluated the programs—and wasn't impressed. "CDC's technical opinion," says Kevin DeCock, director of the agency's AIDS division, "is that name-based HIV surveillance is the system most likely to provide adequate data."

Virtually everyone agrees that Texas's unique-identifier program failed, but Maryland's program has sparked a growing controversy. "We are very pleased with our results," states Liza Solomon, director of the Maryland AIDS Administration. She insists the CDC hasn't fully acknowledged improvements that bring Maryland's system close to the accuracy found in states that use name reporting. Moreover, she says, the unique-identifier system is CONTINUEDON PAGE 44

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SCHOOFS

CONTINUED FROM PAGE 41

showing exactly the trends epidemiologists have been predicting, such as HIV spreading fastest among young women.

The CDC refused to fund implementation of unique-identifier systems, denying four requests from Maryland. Yet the agency has funded states doing name reporting. "That's stacking the deck," charges Ronald Johnson, managing director of Gay Men's Health Crisis. "Hell-bent on name reporting" is how the National Minority AIDS Council's Miguelina Maldonado puts it.

The CDC maintains that Maryland received assistance as part of the evaluation procedure. "We're not hell-bent on anything," says Helene Gayle, the agency's top AIDS officer, "except finding the most effective and efficient method of HIV surveillance."

Name reporting would almost certainly be more efficient, especially in New York City, which has America's largest and most complex HIV caseload, and where many infected people lack Social Security numbers or don't know them. But to Solomon, there is a larger question: "Is there a compelling need for getting HIV information by name? Does that system do so much good that it would balance the privacy rights of people who don't want to give their names, and would it be worth dissuading some people from getting tested? I think not, and I think our Maryland system suggests not."

SOME AIDS ORGANIZATIONS, such as ACT UP, oppose tracking HIV cases even if codes instead of names are used. They point out that the necessary information can be obtained through studies of populations at risk. The government isn't using the information it already has," charges veteran activist Eric Sawyer. "There's no federal needle distribution, even though the epidemic is raging in IV-drug users. Why do they need more information that they won't use?"

Most activists seem to be converging on unique identifiers. But some AIDS advocates are beginning to wonder if they are fighting the right battle. "I don't want to oppose name reporting under false pretenses," says Baker. He

supports unique identifiers, but says, "I don't want people to believe that the greatest threat to privacy is the surveillance system, while at the same time we're advocating for Medicaid, which would put them on a list."

The fact is that almost everyone with HIV ultimately ends up on a list. Except for the very wealthy, everyone who gets a prescription for the expensive new protease inhibitors will go on a private or public insurance registry. In New York and many other states, the welfare rolls tag HIV-positive people in order to give them special services.

The fight, Baker says, is not over whether the government collects names, but how they are used. "Rather than reacting to the fear of what could be in store in some Orwellian world, we have to ask, What kind of system do we want to create?"

Thomas Coates is one of the few AIDS advocates who has come out for name reporting. A veteran epidemiologist and a person with HIV himself, Coates says a concerted effort could make unique identifiers provide reliable data. But, he says, "I don't think it's worth the time and energy. Those funds could be better spent." He adds, "I don't think name reporting is a draconian slippery slope."

Coates might be right—but his position requires a leap of faith that most activists aren't willing to make. They remember innumerable battles against Jesse Helms, Robert Dornan, and Lyndon LaRouche, all of whom tried to stigmatize people with HIV. They also note a general climate of increased government surveillance. The FBI has created a national system of DNA databanks for criminal identification; police cameras watch everyone in public parks; and last year the Clinton administration proposed giving any law enforcement or intelligence agency total access—without a warrant—to any citizen's medical records. In this context, a list of every person who is HIV-positive would clearly be a double-edged sword: It could help monitor the epidemic, or it could scare people away from care and thereby help to spread HIV.

Ultimately, it all depends on how information is used. Will the people on current and future lists be treated as patients in need of care or perpetrators in need of punishment? That's the real battle.

PARINER NOTIFICATION: THE OTHER DEBATE

IN POLITICAL DEBATES, name reporting is almost always linked to partner notification, which works like this: When patients test HIV-positive, they are given the option of informing their partners or of having a public-health worker perform that task, without divulging the patient's name.

Many politicians and editorial writers believe that keeping a registry of everyone who tests HIV-positive will facilitate finding their partners. But a major CDC study discredits that notion. As lead investigator Andy Bindman notes, "no more partners were notified" in states that collect names than in states that don't.

One reason is that waiting for the health department to follow up on people who test positive is not nearly as efficient as counseling patients about partner notification the moment they get their test results. "You can have an excellent partner notification program without name reporting," says Gary West, deputy director of HIV prevention for the CDC.

But a Republican bill in the state assembly would force the health department to follow up on everyone who tests positive, and another bill, sponsored by Democrat Nettie Mayersohn and Republican Guy Velella, would effectively do the same. What's more, the Republican bill would impose criminal penalties on patients who do not

turn over the names of their partners. Right now, notifying partners is voluntary—and activists and public health officials are united in opposing any coercive strategy. "They can't beat the names out of you," notes Bindman. But the threat of criminal penalties could drive many people from testing and prevention programs.

In New York, partner notification is widely regarded as underutilized. Why? "Lack of personnel and resources," says Assemblyman Richard Gottfried. Yet neither the Mayersohn-Velella bill nor the Republican one appropriates any money.

Partner notification is an important service for patients who want to tell their partners but are afraid to face them. But as for curtailing STDs, Bindman notes, "there's very little evidence, if any, to suggest partner notification is a useful strategy."

The CDC's West concurs: "I was unable to find a study that looked at the effect of partner notification on HIV transmission." West believes it could have a "modest" prevention benefit—but only if coupled with other strategies, not if it replaces them. But there's a catch: Partner notification is expensive and labor intensive. If it were paid for by robbing prevention programs known to be effective, it could actually inflame the spread of HIV.

—M.S.